

General

Title

Pediatric kidney disease: percentage of patients aged 17 years and younger with a diagnosis of ESRD on hemodialysis or peritoneal dialysis for whom there is documentation of a discussion regarding advance care planning.

Source(s)

Renal Physicians Association, American Society of Pediatric Nephrology, American Medical Association-convened Physician Consortium for Performance Improvement. Pediatric kidney disease: performance measurement set, measures for accountability. Chicago (IL): American Medical Association; 2011 Aug. 35 p. [26 references]

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Process

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the percentage of patients aged 17 years and younger with a diagnosis of end-stage renal disease (ESRD) on hemodialysis or peritoneal dialysis for whom there is documentation of a discussion regarding advance care planning.

Rationale

The purpose of advance care planning is to help the patient understand his/her condition, identify his/her goals for care, and prepare for the decisions that may have to be made as the condition progresses over time. For chronic dialysis patients, the interdisciplinary renal care team should encourage patient-family discussion and advance care planning and include advance care planning in the overall plan of care for each individual patient.

Patients with decision-making capacity should be strongly encouraged while they have capacity to talk to their legal agents to ensure that the legal agent knows the patient's wishes and agrees to make decisions according to these wishes.

The following evidence statements are quoted verbatim from the referenced clinical guidelines.

Institute family-centered advance care planning for children and adolescents with chronic kidney disease (CKD) and end-stage renal disease (ESRD). The plan should establish treatment goals based on a child's medical condition and prognosis.

Advance care planning should be an ongoing process in which treatment goals are determined and revised based on observed benefits and burdens of dialysis and the values of the pediatric patient and the family. The renal care team should designate a person to be primarily responsible for ensuring that advance care planning is offered to each patient. Patients with decision-making capacity should be *strongly* encouraged to talk to their parents to ensure that they know the patient's wishes and agrees to make decisions according to these wishes. Ongoing discussions that include reestablishing goals of care based on the child's response to medical treatment and optimal quality of life is the mechanism by which advance care planning occurs. Discussions should include pros and cons of dialysis as well as potential morbidity associated with dialysis. Kidney transplantation should also be discussed if appropriate.

Evidence for Rationale

Renal Physicians Association (RPA). Shared decision-making in the appropriate initiation of withdrawal from dialysis. 2nd ed. Rockville (MD): Renal Physicians Association (RPA); 2010 Oct.

Renal Physicians Association, American Society of Pediatric Nephrology, American Medical Association-convened Physician Consortium for Performance Improvement. Pediatric kidney disease: performance measurement set, measures for accountability. Chicago (IL): American Medical Association; 2011 Aug. 35 p. [26 references]

Primary Health Components

Chronic kidney disease (CKD); end-stage renal disease (ESRD); hemodialysis; peritoneal dialysis; advance care planning

Denominator Description

All patients aged 17 years and younger with a diagnosis of end-stage renal disease (ESRD) on hemodialysis or peritoneal dialysis

Numerator Description

Patients for whom there is documentation of a discussion regarding advance care planning (see the related "Numerator Inclusions/Exclusions" field)

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Importance of Topic

Prevalence and Incidence

End-stage renal disease (ESRD), which is a rare but important health problem among children, occurs in about 5 to 10 children per million each year. The disease is a chronic condition; even renal transplantation does not mean lifelong cure. Quality-of-life studies have shown that life without native kidney function is very difficult for children and their families.

Pediatric ESRD patients (less than 20 years of age) constitute a very small proportion of the total ESRD population. However, they pose unique challenges to providers and to the health care system, which must address not only the primary renal disorder but the many extrarenal manifestations that affect growth and development as well. In North America, children younger than 20 years of age account for less than 2% of the total ESRD patient population, and the prevalence of patients aged 0 to 19 years has grown a modest 32% since 1990. This is in contrast to the 126% growth experienced by the entire ESRD population over the same time period.

The prospective, population-based Italkid registry, including almost 1,200 chronic kidney disease (CKD) children with various renal diseases over a 10-year period, reported a prevalence of 23% of patients suffering from severe kidney disease with chronic renal insufficiency (CRI). The incidence of renal replacement therapy was 7.3 per year per 100 patients with CRI, and the risk of developing ESRD by age 20 was 68%.

Mortality

CKD in children is a devastating illness, and the mortality rate for children with ESRD receiving dialysis therapy is between 30 and 150 times that of the general pediatric population. In fact, the expected remaining lifetime for a child 0 to 14 years of age and on dialysis is only 20 years. Early transplantation appears indicated to prevent exposure to the increased risks associated with dialysis therapy. Yet mortality rates among children who undergo transplantation remain in excess of those in the normal population. The challenge ahead is to reduce the incidence of the cardiovascular and malignant diseases that account for the bulk of long-term mortality among children with end-stage renal disease.

Cost

While CKD has been characterized from population-level estimates in the National Health and Nutrition Examination Survey (NHANES) data, much of the disease is silent and unrecognized, complicating any full assessment of its impact.

As identified from diagnosis codes reported on claims, CKD has grown from just 3.3 percent in 1998 to 9.5 percent in 2008.

Costs for CKD patients are now 23 percent of Medicare expenditures in the fee-for-service sector; when added to costs for ESRD patients, it appears that 31 percent of all Medicare expenditures are incurred by patients with a diagnosis of kidney disease.

Despite this high disease burden, the rate of progression to ESRD has been relatively stable over the last several years, suggesting either that CKD patients are dying at a higher rate before they reach ESRD or that their rate of progression to ESRD has slowed.

With Medicare spending for ESRD at \$26.8 billion, and non-Medicare spending at \$12.7 billion, total ESRD costs in 2008 reached nearly \$39.5 billion.

Medicare costs per person per year were nearly \$66,000 overall, ranging from \$26,668 for transplant patients to \$77,506 for those receiving hemodialysis therapy.

In 1993, costs for Medicare patients with CKD accounted for 3.8 percent of overall Medicare expenditures. By 2008, this had grown to 14.2 percent, in part reflecting growth in the number of recognized CKD patients.

ESRD costs rose 13.2 percent in 2008, to \$26.8 billion, and accounted for 5.9 percent of the Medicare budget. Total Medicare spending for erythropoiesis stimulating agents fell 2.3 percent in 2008, to \$1.8 billion. Costs for intravenous (IV) vitamin D hormone increased 12 percent, reaching \$491 million, while spending on IV iron increased 4.8 percent, to \$267 million.

Total hemodialysis expenditures rose 9.3 percent in 2008—up from 3.8 percent in 2007—to reach

\$19.4 billion.

In a national study of primary care physicians and nephrologists, recommendations for laboratory and radiological evaluation of patients with progressive CKD were variable, and few (35%) physicians' recommendations were adherent to established clinical practice guidelines. Most physicians recommended additional testing, which was associated with increased cost of patient evaluations. High levels of additional testing were most common among physicians adhering to guidelines, especially primary care physicians and physicians with fewer years in practice. Both under-testing (nonadherence to guideline recommendations) and additional testing (ordering tests beyond guideline recommendations) contributed to variation with profound cost implications. If patterns of the recommended care observed in this study were extrapolated to reflect patterns of care for patients with incident Stage 3 CKD nationally, the aggregate additional cost of the evaluation for approximately 1 million patients with progressive CKD could amount to \$45 million annually.

Opportunity for Improvement

In 2003, the Council of American Kidney Societies (CAKS) identified 19 barriers to improved patient outcomes in CKD. Rettig, Norris and Nissenson compared the original 19 barriers identified to where things stood in 2007-2008 (see Table 2, "Barriers preventing improved patient outcomes in CKD: The Chronic Kidney Disease Initiative," in the original measure documentation).

In addition, CKD constitutes a microcosm of one of the deepest problems confronting the U.S. health care system: how to move from a system that is focused almost exclusively on procedure-oriented treatment of chronic disease to a system that strikes a reasonable balance between therapeutic and preventive services. Perhaps the modeling contribution of kidney disease of the U.S. health care system is at hand: if this domain of the medical commons can be fixed, then the lessons for the larger system may become clearer for both clinicians and policy makers.

Disparities

A recent report from a selected group of pediatric nephrologists showed that while 73% of white children and adolescents utilized peritoneal dialysis (PD) as their first modality, only 60% of black children and adolescents were initiated on this therapy.

ESRD is more common in certain racial and ethnic groups. African Americans have the highest incidence of treated ESRD in the U.S. Higher rates of kidney disease have been noted in other ethnic groups in the U.S. including Hispanic/Latino Americans, Asian/Pacific Islanders, and American Indians, compared with Caucasians.

African Americans have the highest reported prevalence and incidence of treated ESRD. Overall, African Americans are four times more likely to progress to ESRD compared to whites (988 vs. 254 patients per million) and at a higher-than-average risk for developing ESRD in the Southeastern U.S. Diabetes is the leading cause of ESRD in all racial and ethnic groups, but occurs at a much higher rate among African Americans, Hispanics and Native Americans (422, 382.9, and 307.2 vs. 115 per million, respectively) compared to whites. In addition, African Americans have the highest rate of hypertension-related ESRD, which far exceeds other racial and ethnic groups. As a result, hypertension remains a close second to diabetes mellitus (DM) as the leading cause of ESRD in the African-American community.

Hispanic Americans have a diabetes rate more than twice that of whites, and are twice as likely to progress to ESRD than whites. Furthermore, the higher prevalence of diabetes among Hispanic individuals is only partially explained by the increased rate of ESRD progression.

Registry level data from the United States Renal Data System (USRDS) show that U.S. Asians have a 34% higher age and gender adjusted risk of ESRD compared to U.S. whites and have a 12-fold increase in the prevalence of ESRD since 1980.

The American Indian (AI) and Alaska Native (AN) population of the U.S. was estimated to be 3.3 million people in 2007, a 65% increase from the 1990 population of 2 million. Diabetes prevalence among AI/AN is 2.2 times higher than for non-Hispanic whites and more than 16% of all AIs/ANs aged 20 years and older are diabetic. In some tribes, such as the Pima and Zuni, 30%–50% of the

adult population is diabetic. More than two thirds of AIs/ANs who initiated treatment for ESRD in 2005 developed kidney failure also had a diagnosis of diabetes, virtually all (95%) Type 2. By the end of 2005, the prevalence of ESRD among AI/AN was 2.3 times greater than that of non-Hispanic white Americans.

In the U.S., black individuals shoulder a disproportionate burden of end-stage renal disease, comprising 32% of the end-stage renal disease population, but only 13% of the general population. ESRD is one of the most dramatic examples of health disparities, with rates for minorities ranging from 1.5 to 4.0 times those of age-adjusted white counterparts, despite similar rates for the early stages of CKD. Although CKD is associated with increased rates of premature mortality, adjusted ESRD survival rates are paradoxically better for minorities.

More than one third of U.S. dialysis patients are black, a threefold over-representation. The mortality of dialysis patients with ESRD is approximately 21% annually. In contrast to the course of other chronic illnesses in the U.S., black dialysis patients enjoy improved survival compared with white patients. This paradoxical difference is unexplained by socioeconomic status or currently identified biological factors. A reasonable hypothesis would suggest psychosocial factors underlie this dramatic disparity.

The Physician Consortium for Performance Improvement (PCPI) believes that performance measure data should be stratified by race, ethnicity, and primary written and spoken language to assess disparities and initiate subsequent quality improvement activities addressing identified disparities. These categories are consistent with recent national efforts to standardize the collection of race and ethnicity data. A 2008 National Quality Forum (NQF) report endorsed 45 practices including stratification by the aforementioned variables. A 2009 Institute of Medicine (IOM) report "recommends collection of the existing Office of Management and Budget (OMB) race and Hispanic ethnicity categories as well as more fine-grained categories of ethnicity (referred to as granular ethnicity and based on one's ancestry) and language need (a rating of spoken English language proficiency of less than very well and one's preferred language for health-related encounters)."

The vast majority of patients with CKD die in acute care facilities, without accessing palliative care services. Questions around the issue of advance care planning showed that patients are comfortable discussing end-of-life issues with both family (69.7%) and nephrology staff (65.6%). However, 90.4% of patients reported that their nephrologist had not discussed prognosis with them, and only 38.2% had completed a personal directive.

Most of the patients (51.9%) reported not having had discussion regarding end-of-life care preferences in the past 12 months, with less than 10% having had such a discussion with their nephrologist. Almost 50% of patients wanted to have these discussions with their nephrologist, 39% with their family doctor, and 20% wanted to involve their nephrology nurse. Patients felt that these discussions should be ongoing when the need arose (as defined by the medical team).

Evidence for Additional Information Supporting Need for the Measure

Charles RF, Powe NR, Jaar BG, Troll MU, Parekh RS, Boulware LE. Clinical testing patterns and cost implications of variation in the evaluation of CKD among US physicians. *Am J Kidney Dis*. 2009 Aug;54(2):227-37. [PubMed](#)

Choi AI, Rodriguez RA, Bacchetti P, Bertenthal D, Hernandez GT, O'Hare AM. White/black racial differences in risk of end-stage renal disease and death. *Am J Med*. 2009 Jul;122(7):672-8. [PubMed](#)

Cukor D, Kimmel PL. Education and end of life in chronic kidney disease: disparities in black and white. *Clin J Am Soc Nephrol*. 2010 Feb;5(2):163-6. [PubMed](#)

Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol*. 2010 Feb;5(2):195-204. [PubMed](#)

Furth SL, Powe NR, Hwang W, Neu AM, Fivush BA. Racial differences in choice of dialysis modality for children with end-stage renal disease. *Pediatrics*. 1997 Apr;99(4):E6. [PubMed](#)

McDonald SP, Craig JC, Australian and New Zealand Paediatric Nephrology Association. Long-term survival of children with end-stage renal disease. *N Engl J Med*. 2004 Jun 24;350(26):2654-62. [PubMed](#)

Norris K, Nissenson AR. Race, gender, and socioeconomic disparities in CKD in the United States. *J Am Soc Nephrol*. 2008 Jul;19(7):1261-70. [96 references] [PubMed](#)

Palmer Alves T, Lewis J. Racial differences in chronic kidney disease (CKD) and end-stage renal disease (ESRD) in the United States: a social and economic dilemma. *Clin Nephrol*. 2010 Nov;74 Suppl 1:S72-7. [PubMed](#)

Race, ethnicity, and language data: standardization for health care quality improvement. AHRQ publication no. 10-0058-EF. [internet]. Rockville (MD): Agency for Healthcare Research and Quality; 2010 Mar [accessed 2011 May 16].

Rettig RA, Norris K, Nissenson AR. Chronic kidney disease in the United States: a public policy imperative. *Clin J Am Soc Nephrol*. 2008 Nov;3(6):1902-10. [PubMed](#)

U.S. Renal Data System. USRDS 2010 annual data report: atlas of chronic kidney disease and end-stage renal disease in the United States. Bethesda (MD): National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2010.

Warady BA, Chadha V. Chronic kidney disease in children: the global perspective. *Pediatr Nephrol*. 2007 Dec;22(12):1999-2009. [PubMed](#)

Wuhl E, Schaefer F. Therapeutic strategies to slow chronic kidney disease progression. *Pediatr Nephrol*. 2008 May;23(5):705-16. [111 references] [PubMed](#)

Extent of Measure Testing

Several of the measures presented here represent updates to existing measures for chronic kidney disease (CKD) and end-stage renal disease (ESRD). They have been utilized in the adult population, in their previous specifications, in national performance measurement projects such as the Centers for Medicare & Medicaid Services (CMS) Physician Quality Reporting Initiative (PQRI) project. In addition, specific research projects, including a project Physician Consortium for Performance Improvement (PCPI), have been conducted to test the reliability of these measures in an adult population in various settings. Results of these testing projects have been considered and resulted in modifications to the measures, where appropriate.

Feasibility Testing

The PCPI measure testing project found the measures to be feasible in the adult population. Their use in the PQRI program also indicates general feasibility in the adult population.

Reliability Testing

The PCPI measure testing project in the adult population found the measure reliability in the almost perfect range. For CKD measures, kappas ranged from 0.89 to 0.99. For ESRD measures, kappas ranged from 0.96 to 0.99. Agreement percentages from interrater reliability testing ranged from 95.5% to 99.8%.

Other measures in the set are being made available without any prior testing. The PCPI recognizes the importance of testing all of its measures and encourages testing of the Kidney Disease measurement set

by organizations or individuals positioned to do so. The Measure Testing Protocol was most recently approved by the PCPI in 2011 and is available on the PCPI Web site (see Position Papers at www.physicianconsortium.org); interested parties are encouraged to review this document and to contact PCPI professional staff. The PCPI will welcome the opportunity to promote the initial testing of these measures and to ensure that any results available from testing are used to refine the measures before implementation.

Evidence for Extent of Measure Testing

Renal Physicians Association, American Society of Pediatric Nephrology, American Medical Association-convened Physician Consortium for Performance Improvement. Pediatric kidney disease: performance measurement set, measures for accountability. Chicago (IL): American Medical Association; 2011 Aug. 35 p. [26 references]

National Guideline Clearinghouse Link

[Guideline recommendations and their rationales for the treatment of adult patients. In: Shared decision-making in the appropriate initiation of and withdrawal from dialysis, 2nd edition.](#)

State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Ambulatory/Office-based Care

Ambulatory Procedure/Imaging Center

Hospital Outpatient

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Individual Clinicians or Public Health Professionals

Statement of Acceptable Minimum Sample Size

Unspecified

Target Population Age

Age less than or equal to 17 years

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Person- and Family-centered Care

Prevention and Treatment of Leading Causes of Mortality

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Equity

Patient-centeredness

Data Collection for the Measure

Case Finding Period

Unspecified

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Clinical Condition

Patient/Individual (Consumer) Characteristic

Therapeutic Intervention

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions

All patients aged 17 years and younger with a diagnosis of end-stage renal disease (ESRD) on hemodialysis or peritoneal dialysis

Exclusions

None

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions

Patients for whom there is documentation of a discussion* regarding advance care planning

Note: Although the discussion can take place with other providers, the physician overseeing the dialysis should confirm that the conversation has been undertaken either [i] directly by the nephrologist or dialysis center staff, or [ii] by another physician overseeing the patient's care.

*Discussion should result in a plan to establish treatment goals based on patient's medical condition and prognosis. Discussion must endorse a family centered approach, and treatment goals must be determined. The benefits and burdens of dialysis should be discussed, and the quality of the life of the individual be taken into account. Kidney transplant should be discussed if appropriate.

Exclusions

None

Numerator Search Strategy

Fixed time period or point in time

Data Source

Electronic health/medical record

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Unspecified

Computation of the Measure

Measure Specifies Disaggregation

Does not apply to this measure

Scoring

Rate/Proportion

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

Measure #4: discussion of advance care planning.

Measure Collection Name

Pediatric Kidney Disease Performance Measurement Set

Submitter

Renal Physicians Association - Medical Specialty Society

Developer

American Society of Pediatric Nephrology - Medical Specialty Society

Physician Consortium for Performance Improvement® - Clinical Specialty Collaboration

Renal Physicians Association - Medical Specialty Society

Funding Source(s)

Unspecified

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Financial Disclosures/Other Potential Conflicts of Interest

None of the members of the Kidney Disease Work Group had any disqualifying material interests under the Physician Consortium for Performance Improvement (PCPI) Conflict of Interest Policy. A summary of non-disqualifying interests disclosed on Work Group members' Material Interest Disclosure Statements (not including information concerning family member interests) is provided in the original measure documentation. Completed Material Interest Disclosure Statements are available upon request.

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2011 Aug

Measure Maintenance

The Physician Consortium for Performance Improvement (PCPI) stipulates a regular review of measures every 3 years or when there is a major change in scientific evidence, results from testing, or other issues noted that materially affect the integrity of the measures.

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

The measure developer reaffirmed the currency of this measure in March 2016.

Measure Availability

Source not available electronically.

For more information, contact the Renal Physicians Association (RPA) at 1700 Rockville Pike, Suite 220, Rockville, MD 20852; Phone: 301-468-3515; Fax: 301-468-3511; E-mail: rpa@renalmd.org; Web site: www.renalmd.org .

NQMC Status

This NQMC summary was completed by ECRI Institute on August 24, 2012. The information was verified by the measure developer on November 5, 2012.

The information was reaffirmed by the measure developer on March 11, 2016.

Copyright Statement

This NQMC summary is based on the original measure, which is subject to the measure developer's copyright restrictions.

For more information, contact the Renal Physicians Association (RPA) at 1700 Rockville Pike, Suite 220, Rockville, MD 20852; Phone: 301-468-3515; Fax: 301-468-3511; E-mail: rpa@renalmd.org; Web site: www.renalmd.org .

Production

Source(s)

Renal Physicians Association, American Society of Pediatric Nephrology, American Medical Association-convened Physician Consortium for Performance Improvement. Pediatric kidney disease: performance measurement set, measures for accountability. Chicago (IL): American Medical Association; 2011 Aug. 35 p. [26 references]

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